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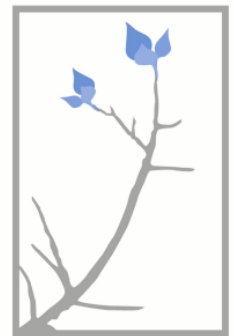
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Decision Making in HD: Uncertainty, Unawareness, and Denial

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Uncertainty

At risk individuals: do I have the gene? If so, when does the disease start?

Partner of at risk individual: my loved one has become irritable and distant. Is this a relationship issue or is it the onset of HD?

Caregiver: my loved one is unwilling to give up the checkbook, keys, responsibility for child care, etc. How do I provide the proper care?

Affected individuals: will I lose myself? Who am I if I am no longer the breadwinner, etc? How will I take care of myself and who will help me?

Denial

- A defense mechanism used by most of us at one point or another characterized by refusal to acknowledge a painful fact.
- Thought to be an unconscious process, but the most accessible defense in terms of intervention.
- Ego is trying to help us, but the avoidance often prevents addressing an appropriate course of action.

Anosognosia

- A=without + nosos=disease +(a)gnosia =awareness.
- Lack of awareness of physical symptoms due to brain changes.
- Caused by disruption of basal ganglia/frontal lobe circuit. [Not by the person's deliberate attempt to be difficult.]
- One of the most problematic symptoms in HD.

Attribution

- What we perceive as the reasons for another's behavior often determines our responses to that behavior.
- Elements in our perception of reasons for another's (or our own) behavior: locus (external v. internal); stability; controllability. [B. Weiner]
- Ex: If the refusal to recognize HD sx in oneself is actually due to brain changes rather than a deliberate attempt to be difficult, the caregiver can avoid taking this personally and move on to:

Decision Making

- How to get the job done, i.e., the neurological exam arranged and attended, the bath accomplished, the keys relinquished.
- Spouse whose behavior has changed- seek marital counseling, consider neurological eval
- Anxious at risk person- consider genetic testing, psychotherapy, changing situational stressors.